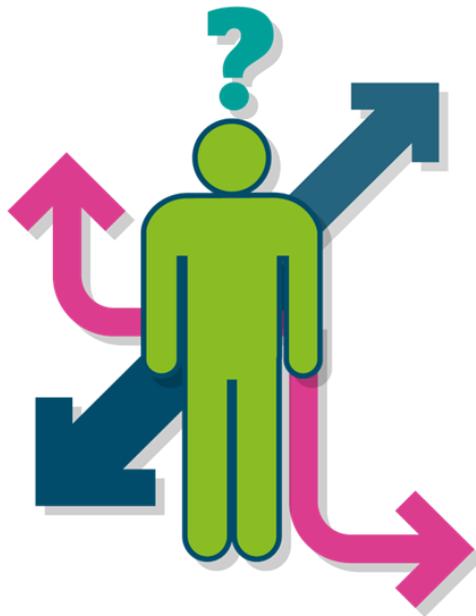


*“It will take time for many people to understand and trust that ‘joined up care’ actually works”*



How people experience joined up care in Oxfordshire

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# Contents

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Contents .....	2
Executive summary.....	3
1 Background.....	5
2 Methods.....	6
3 Results.....	7
3.1 Who did we hear from? .....	7
3.2 What did we hear? .....	8
3.2.1 What does joined up care look like to you? .....	8
Everyone working together .....	9
Sharing information and ideas .....	10
Person-centred care .....	10
Seamless care.....	11
3.2.2 How do people experience joined up care?.....	11
Positive experiences.....	11
Services not working together .....	12
Care is not always patient-centred.....	14
Inadequate delivery of care.....	16
3.2.3 What works well? .....	16
3.2.4 What could be better or different?.....	18
3.3 Case stories .....	18
4 What did we learn? .....	20
5 Useful links .....	21

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# Executive summary

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In May 2023, Healthwatch Oxfordshire conducted a survey to find out about local people's ideas and experiences of 'joined up' care. It asked four open-ended questions:

- 1. What does 'joined up care' look like to you?**
- 2. Tell us about your experience of joined up care. (For example, how your care was managed between different health and care services and what this was like for you?)**
- 3. What works well?**
- 4. What could be better, or different?**

This report summarises the responses of 38 completed questionnaires and follow-up interviews with five people. Most participants were white British and aged over 65 years, therefore the findings do not necessarily reflect the experiences of people from other backgrounds and communities.

## What we heard

### 1. What does 'joined up care' look like?

People tended to describe 'joined up' care in the following terms:

- Everyone working together
- Sharing information and ideas
- Person-centred care
- Seamless care

'Everyone working together' involved providers and services across health and social care working with each other to meet service users' needs. 'Sharing information and ideas' included ensuring access to data and patients' medical records. It also required good communication between services and service users and caregivers. 'Person-centred care' meant treating the patients as a 'whole person' and prioritising their beliefs and preferences for their care. People who said joined up care should be 'seamless' felt that different organisations and providers would effectively act as a single entity, with invisible boundaries between them.

### 2. How do people experience joined up care?

Positive experiences included some examples of services working together and effectively communicating. However, most people had less favourable experiences, many sharing examples of fragmented care, inadequate

communication, and significant challenges navigating the care system, especially in complex cases or when multiple services were involved.

People sometimes felt that the care they received was not patient-centred, including providers not listening, or treating them more as a health condition than a person with a condition. There was also the sense that decisions were often made *about* them rather than *with* them. People also pointed to deficiencies in the delivery of health and social care, including poor access to some services as well as a lack of openness and transparency in decision-making.

### **3. What works well?**

When different providers were willing to work with others and when services worked together, people felt more supported and experienced better care. Other people mentioned individual providers or specific services that had supported them or provided good quality care. Family members who could help navigate the health and social care system were also valued.

### **4. What could be different or better?**

Suggestions for improvement centred on:

- Services working more closely together, especially between health and social care.
- A recognition that services users and caregivers are not experts in the health and social care system and may be unfamiliar with the terminology that professionals use.
- Better communication, involvement and information sharing of and to patients and families about care, and emerging joined up care in the county.
- Better communication and information-sharing among providers, and ensuring health records were read and updated on the NHS app.
- Greater transparency regarding social care structures and decision-making.
- Ensuring a dedicated or 'named' 'patient advocate' responsible for coordinating with providers, patients, and caregivers across services.
- More available services to improve access to care, including GP appointments, mental health support, local x-ray facilities, and patient transport service.

We will share this report with health and social care providers, the Oxfordshire Health and Wellbeing Board and Oxfordshire Place Based Partnership.

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# 1 Background

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People are living longer and with more complex health conditions and social needs, which are different in different places. Their various needs cannot effectively be addressed by individual services or practitioners one-by-one, and require a response that integrates services, focuses on the person, and tailors support to the local context.<sup>1</sup>

A central theme of the NHS Long Term Plan<sup>2</sup> is to develop a system of joined up care between health and social care services. The benefits of this approach are to help patients get timely, appropriate, and holistic care based on their needs, to avoid being passed to multiples services, and to avoid having to repeat their story to different providers. The 2022 Health and Care Act aims to make this easier in England through the creation of Integrated Care Systems (ICSs). ICSs are partnerships between NHS organisations, local authorities, and other organisations including voluntary sector that have the responsibility of improving health across a defined region.

Oxfordshire is part of the Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) and wider Integrated Care Partnership (ICP). BOB ICP has developed an *integrated care strategy* towards meeting the challenges outlined above. It commits to following five principles:

- Preventing ill health
- Tackling health inequalities
- Providing person-centred care
- Supporting local delivery
- Improving the join up between services

Oxfordshire Place Based Partnership, under BOB ICB, is Oxfordshire focused, and acts as a consultative forum bringing together health and care system representatives and others, in order to increase collaboration, joined up approaches to care and explore ways to use collective resources to improve outcomes of residents. It builds on work that has taken place between health and social care to further joint planning, including pooled budgets (Section 75 agreement between BOB ICB and Oxfordshire County Council) and other joint working agreements across services.

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<sup>1</sup> <https://www.scie.org.uk/integrated-care/better-care/guides/work-together/case>

<sup>2</sup> <https://www.longtermplan.nhs.uk/>

Evidence of more integrated ways of working in Oxfordshire between health, social care, and others, including voluntary sector partners, have been emerging in the past few years. COVID also brought services closer together and supported better communication and more integrated ways of working. For example, models of hospital discharge, use of Single Point of Access and emphasis on a 'home first' approach, work under the Better Care Fund, and support from voluntary sector groups involve daily collaboration between health, social care and voluntary sector and families and patients (see appendix for further information).

As these models develop, Healthwatch Oxfordshire wanted to gain a snapshot at this point in time of what people in Oxfordshire thought 'joined up' care meant and how they had experienced it. This research report presents the results of a brief survey and follow-up telephone interviews that explored these issues with some of Oxfordshire's residents. Thanks to all who contributed.

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## 2 Methods

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In May 2023, Healthwatch Oxfordshire ran a brief online survey inviting people across the county to share their thoughts and experiences as patients of joined up care. It focused on four open-ended questions:

- 1. What does 'joined up care' look like to you?**
- 2. Tell us about your experience of joined up care. (For example, how your care was managed between different health and care services and what this was like for you?)**
- 3. What works well?**
- 4. What could be better, or different?**

The survey was promoted in Healthwatch Oxfordshire's regular news briefing and via social media, as well as being circulated to GP surgery Patient Participation Groups (PPGs) and other organisations for them to share with their networks. Articles were also published in Pulse newsletter and on the LiveWell website. A poster used to promote the survey is shown above.

People were asked in the survey whether they would be happy to talk in more detail about their experiences. Five people who agreed participated in a telephone interview by a representative of Healthwatch Oxfordshire. The interviews were recorded and written up anonymously to protect the participants'

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**What does  
'joined up'  
care look  
like to you?**



**NHS health and care services are moving towards more 'joined up' care for patients**

Share your experience of joined up care by completing our anonymous survey at [www.smartsurvey.co.uk/s/yourjoinedupcare](http://www.smartsurvey.co.uk/s/yourjoinedupcare) or by scanning the QR code below



**healthwatch**  
Oxfordshire

Your voice on health and care services

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identities. The information collected in the surveys and personal stories were combined and analysed to look for common themes and other feedback that seemed important to be included in this report.

## 3 Results

### 3.1 Who did we hear from?

Thirty-eight people completed a survey questionnaire and five people took part in a telephone interview. A profile of the survey participants is given in the tables and figures below. Table 1 summarises participants by age group. We have also added three additional comments of relevance from people about joined up care, which were gathered from our outreach and online feedback.

**Table 1. Survey participants by age group**

Age group	Number	Percent
18-24	0	0%
25-49	5	13%
50-64	11	29%
65-79	15	39%
80 or over	4	11%
Prefer not to say/no answer	3	8%
<b>Total</b>	<b>38</b>	<b>100%</b>

Most people were in the 65-79 age group, followed by 50 to 64-year-olds. Twenty-eight people (76%) identified as women and five (14%) as men, while four (11%) preferred not to say. Table 2 summarises participants by their ethnic group.

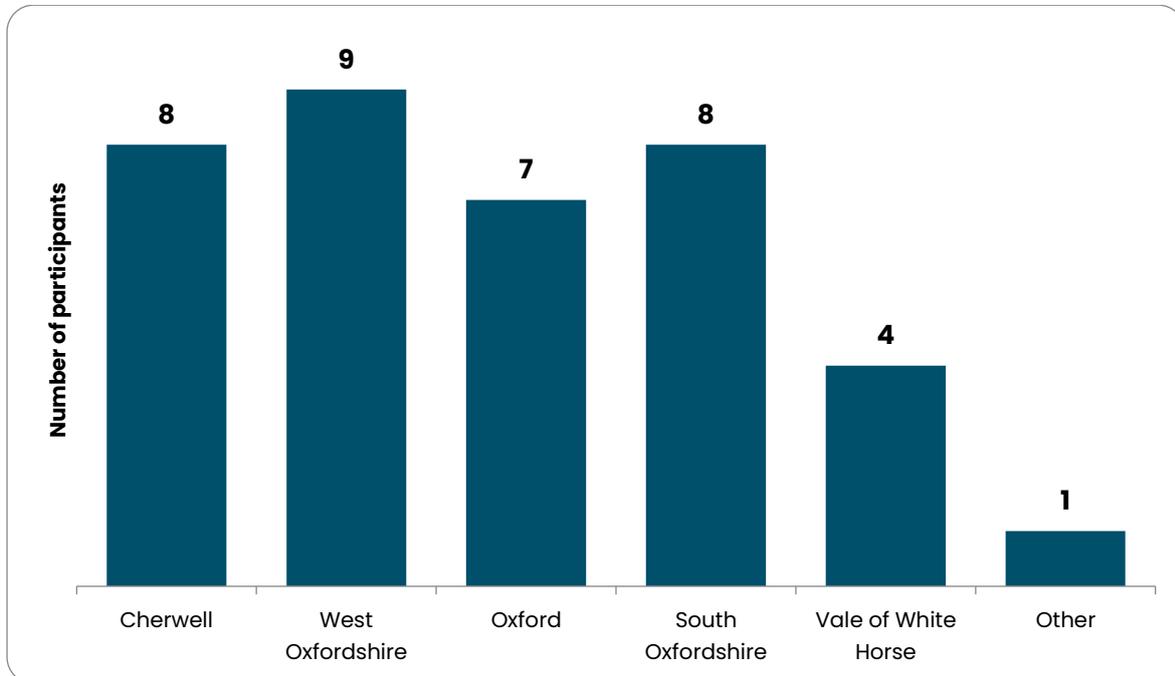
**Table 2. Survey participants by ethnicity**

Ethnicity	Number	Percent
Mixed/Multiple ethnic groups: Asian and White	1	3%
Mixed/Multiple ethnic groups: Any other Mixed/Multiple ethnic groups	1	3%
White: British/English/Northern Irish/Scottish/Welsh	28	74%
White: Irish	1	3%
White: Gypsy Irish/Traveller	1	3%
White: Any other White background	1	3%
Prefer not to say/no answer	5	13%
<b>Total</b>	<b>38</b>	<b>102%</b>

Note: Total percent is more than 100% due to rounding

Twenty-eight people (74%) said they were White British, five did not disclose their ethnicity, two were from mixed or multiple ethnic groups, and three were from Irish or other white backgrounds.

**Figure 1. Survey participants by district**



37 people responded to the question. They were fairly evenly distributed across Oxfordshire's five districts, except for Vale of White Horse where only four people responded. One person who answered 'Other' was reporting their experience of receiving health care in Oxfordshire but lived in a neighbouring county.

## 3.2 What did we hear?

This section presents the range of views and experiences that people reported in their survey responses.

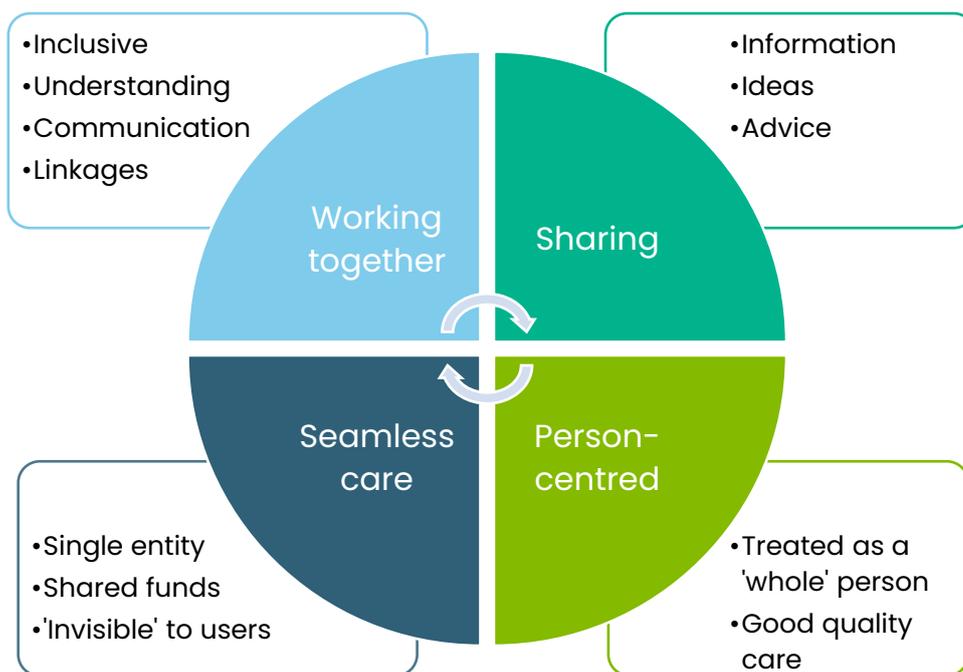
### 3.2.1 What does joined up care look like to you?

Responses suggested at least four broad areas of understanding:

- Everyone working together
- Sharing information and ideas
- Person-centred care
- Seamless care

A model of these four broad areas and their defining characteristics are shown in figure 2 below.

**Figure 2. Perceptions of joined up care**



When people reflected on the idea of joined up care, they usually highlighted more than one meaning, emphasising that is not a single concept but a combination of characteristics.

### **Everyone working together**

Responses to the question about what joined up care 'looked like' showed a strong sense that it meant that everyone involved in a person's care would work with each other to meet service users' needs. Comments included:

*"It should be all services coming together to meet the needs of the individual patient."*

*"Different departments working together to ensure that the needs of the person being supported are met in a caring, supportive manner...including the person they are supporting, along with their carers in the process. Everyone involved having an understanding, training in supporting those with special needs, and empathy."*

One person identified different services as, "including primary care and secondary care as well as commissioned and common voluntary and community sector services." As the quote above indicates, some people also felt that patients and caregivers must also be included.

Part of working together included everyone understanding the person's needs as well as knowing who else was involved in their care and what everyone was doing:

*“All hospital departments and my GP knowing what each other are prescribing and how they will interact with other treatments I’m having. All being aware I’m under the care of the others.”*

People explained that everyone *“understanding what [the] next steps are”* was necessary to effectively plan and coordinate appropriate care that would meet the person’s needs.

Other people commented that joined up care meant having close linkages between different care providers as well as *“clear referral pathways”* between primary, secondary, and social care.

### **Sharing information and ideas**

Alongside working together, some people saw the sharing of information relevant to the person’s condition and care as important. This included comments like shared access to *“a common database”* and to medical records:

*“Where all the professionals have access to medical records. A central place to add notes etc. on a patient.”*

*“Coherent and consistent data transfer between hospitals, doctors and other care professional to enable the needs of the individual patient to be addressed correctly and completely.”*

Others highlighted *“sharing ideas and advice”* about how best to meet the person’s needs, especially when they are complex.

Sharing information implied effective communication within and across services, as well as with patients and their caregivers:

*“Joined up care would be good communication between the services I interact with and with me.”*

Communication between everyone was seen as important in all areas of care to ensure *“the best outcomes for the person they support.”*

### **Person-centred care**

A third aspect of joined up care focused everyone working together *“for the best outcomes for the person they support”*. This meant prioritising service users’ beliefs and preferences over those of the health care providers. For example, one person said:

*“Joined up care looks like agencies all thinking about what the patient needs to stay in their own home, not what health care professionals think is best in theoretical terms.”*

People said they wanted to be treated as a “*whole person*” rather than reduced to a health condition or care need. People with multiple health conditions wanted those supporting them to look at their needs together rather than separately. One person felt that it didn’t matter which health or social care organisation was involved in providing care, as long as it was good quality and provided on time.

### **Seamless care**

A number of people felt that joined up care would be “*seamless*” throughout the person’s journey through the care system. This meant that, in a truly integrated care system, different organisations and providers would effectively act as one, and that the boundaries between them would be invisible to the service user. As one person put it:

*“If services were truly joined up, one wouldn’t know when one moves between them, they would seem like a single entity.”*

*“system as a whole doesn’t connect, they don’t know what medications you are on, and don’t connect holistically, especially important for cancer care, as has so much impact on family and on the body - continuity of care across services not great.”*

*(Feedback via outreach visit to hospital)*

For a few people, an element of joined up care meant sharing health and social care budgets. This involved:

*“Health paying for care when a person needs care due to an illness and is not in hospital but cared for at home or in a care setting.”*

This example probably relates to the complex eligibility for Continuing Health Care (CHC) and the difficulties that people often face when seeking CHC support.

### **3.2.2 How do people experience joined up care?**

#### **Positive experiences**

Positive experiences included, “*Generally in Oxford, it is all managed really well*” and, “*LD [Learning Disability] Health have been brilliant with transition from child to adult services.*”

One person said:

*“With the changing ways in which we access GP’s and their services, it is important to understand that the GP is not necessarily the right person to see under every circumstance.”*

For this person, having access to a range of health professionals meant that they could get the most appropriate help for their situation and would only need to

contact their GP if their symptoms became more serious. Clear communication was also key.

Two people who had needed treatment from more than one provider said that they had communicated with each other and coordinated well to ensure their recovery:

*"...the diabetes team were aware of what the MS team were doing and all correspond well."*

*"When I went in for my hip replacement and got pneumonia how both doctors worked together with each other to ensure that I recovered from both well."*

*"System works well. Tedious wait for phone contact, thereafter system works well. See doctor, diagnosis, referrals as necessary. Hospitals communicate with us and doctor. Physio app is great way of getting speedy physio. Hospitals and surgery communicate well. Full of praise for doctor, surgery and hospitals, all working under duress."  
(Online review via our service feedback link).*

We also heard a comment which highlighted positive experience of joined up care in discharge from hospital and support for transition to home,

*"We had a great experience with my 86 year old dad being admitted to emergency medical unit (EMU) in Abingdon with joined up care being made available to him afterwards from hospital at home. The team were welcoming and friendly and kept us so well informed all of the time, allowing us to speak to a range of professionals and doing their best to keep my dad at home rather than being admitted to the John Radcliffe."  
(Online review via our service feedback link)*

In contrast with the positive comments above, other survey responses suggested that people experienced a variety of problems and barriers, while some people said that their care had not been 'joined up' at all. The main problems and challenges people experienced are described below.

### **Services not working together**

We found numerous examples where health or social care services appeared not to be working in an integrated way. For example, two people commented that their social care teams seemed unwilling to collaborate with other services, while others said that communication was poor. One person noted, *"It feels like each team is independent, they do not communicate with each other."*

Other examples included providers not sharing information such as records of previous appointments, X-ray results, or other useful information:

*“If you’re unlucky enough to have to move between organisations then almost certainly you’ll have to wait months or years and the two organisations won’t have any shared notes or expertise.”*

When services did not seem to be collaborating or communicating with each other, service users were left to follow up on referrals without enough knowledge or information:

*“Access to other services...has all been referred separately then left with the patient to follow up, not knowing what expected timelines are, what information has already been shared, who is responsible for booking or following up, e.g. blood tests. Many next steps have involved going back through primary care, where there is no named GP, full background and context is shared to Health Navigators often with misunderstanding of how an individual need relates to the wider picture of a complex condition.”*

*“I have had to liaise and pass information on to other teams looking after me. It would be far more efficient if clinicians emailed each other. I fear important information may be missed or misinterpreted.”*

As the quotes above highlight patients and caregivers can experience significant challenges navigating the care system, especially in complex cases or when multiples services are involved.

Two people said that their elderly relatives had been discharged from hospital without an adequate care package in place. Others reported having to phone many times to find information or chase services for the support they needed. One person said, *“Care for my mother was a nightmare and a fight to get the care I needed.”*

People often experienced the process of being seen by different services or providers as *“long-winded”* and somewhat wasteful, each time requiring them to repeat the same information. One person who was waiting for a hip replacement said:

*“My GP started the ball rolling but in a year I have been sent to see consultants, recommended for physio, more consultants, each one saying ultimately you need surgery. So why am I wasting time and money attending these appointments and the NHS wasting money?”*

People using both health and social care reported similar accounts. When services and providers did not work together, people felt that they were *“batted back and forward between both services.”* Several commented that neither

service seemed to take overall responsibility for decisions or commit to funding their care. For example:

*"I found the process was long and drawn out, with one service taking the lead then choosing to help fund then changing their mind and then transferring to another service who will now probably refuse to help or pay less. It's about sharing the information for their needs (service) to bat the vulnerable person who needs services around to see who will fund it and then leave them with nothing or bad care packages."*

Other people commented that when they used different health services, the providers did not refer to their medical records:

*"I have complex health issues. I see many different consultants some don't bother to read my health records."*

*"Not once have my medical notes been read or referred to, other professional have no idea what is happening."*

People who used services in a neighbouring county experienced problems of providers not working together cross boundary, sharing resources, or taking overall responsibility for their care:

*"A relative was stuck in hospital for months because there was no agreement as to who was responsible for her social care (she lived in one health district, her GP was in a different one) and sadly she died in a 'respite' hospital before she could be moved somewhere more suitable."*

Two others said that the providers had not sharing information or communicated with each other after they were discharged from hospital.

### **Care is not always patient-centred**

Survey responses suggested that people did not always experience patient-centred care. Patients and their caregivers sometimes felt that "health professionals [were] not listening" or that care providers did not adequately consider their wishes in decisions that affected them. Some responses suggested that patients how need various services experience multiple decisions and might not be unable to advocate for themselves:

*"Too many decisions are made about people by too many different people. For example, a person may attend A&E and have decisions made for them, they are then passed to a medical ward where more decisions are made, they are then discharged from hospital and more*

*decisions are made. If patients do not have a well-informed family member who is a strong advocate for them decisions are made which work for the system but do not best suit."*

The quote above gives the sense that decisions in health and social care are often made *about* people rather than *with* them. One caregiver also said:

*"...we are at the mercy of different agencies and what they think is right. The individual is not considered when new equipment is imposed on a patient, significantly changing their home environment. We need a 'patient focus' approach from all the agencies not a 'condition approach', i.e. 'This is what condition she has so therefore this will happen' etc...The care companies and the Occupational Health dept seem to override patient wishes."*

The person in the quote above suggested that care providers tend to treat service users as their health condition or specific need rather than a whole person. Others echoed this view, with one person saying they were, *"fed up with being treated as a knee replacement, hip replacement, live kidney donor, or painful back."*

Similarly, other survey responses showed that people sometimes perceived that decisions were made to fit the system more than the patient's needs:

*"It isn't joined up for us 'the end user'. The 'joined upedness' only really suits those who are in control of the system."*

*"It does nothing for the person needing support always for the advantage of the services."*

One of the reasons why people experience decision-making in this way is the possibility that care providers might forget that service users and caregivers will not necessarily understand the health and social care systems, and the range of different providers.

Some people perceived that caregivers were expected to understand the health and care system or it was assumed that they knew. However, one person said, *"many people have no idea how the system works and where to go for help"*. Another said that it was:

*"Not easy to navigate the systems. How do you expect vulnerable persons to understand when the system is working in a way that is not correct and them to know what is going on when the service are not acting in their best interests?"*

A participant who had experience as a health care professional also commented that:

*“...family members have to act as an advocate and when they do not have the knowledge or skills to do this (and even sometimes when they do) often poor decisions are made in the here and now without enough consideration of the future.”*

### **Inadequate delivery of care**

Some deficiencies in aspects of the delivery of care seemed to influence people’s perceptions and experiences of joined up care. One of these was a lack of resources to provide comprehensive care. Comments included:

*“Lack of carers who are well trained. But the carers were mostly caring and knew what to do but so much they were not allowed to do.”*

*“Care is virtually non-existent in Oxfordshire so it can’t possibly be joined up. It is incredibly hard to see any health or care professional of any description.”*

One person who lived in a rural part of Oxfordshire talked about a lack of follow-up care for a relative who was transferred to a care home for assessment. They said:

*“Many promises were made by Social Services about regular (3 and even 4 times a day) visits for medicine, etc - but less than 50% of these daily visits promised happened because in the rural areas there are not the organisations to support the promises made.”*

Other people felt that there was a lack of openness and transparency in some decisions, especially those around social care funding:

*“The financial assessment team appear to be lacking in information on how they calculate contributions - or unwilling to share this information.”*

*“Care for my mother was a nightmare and a fight to get the care needed. It took a Consultant to tell me that health should have been paying for mum’s care. There is a lack of transparency.”*

### **3.2.3 What works well?**

Several people who described having problems with their health or social care gave negative or dismissive comments. Some were unsure how to answer or suggested that “nothing” was working well, while others picked out aspects of care that had not worked for them, such as lack of funding for social care, poor quality care agencies, and difficulty seeing a GP.

However, we heard that when different providers were willing to work with others and when services worked together, people felt more supported and experienced better care:

*"LD Health are willing to work with everyone to support the young person and their carers."*

*"NHS and Social Care working together in one team."*

*"NHS End-of-Life Administration which coordinated well with Home Caring Company."*

Other people mentioned individual providers or specific services that had supported them or provided good quality care. These included GPs and reception staff, social workers, carers, outpatient clinics, and local charities. One example was help given by hospice staff to access various types of care:

*"...the advice and ad hoc calls from this team has helped to progress several referrals to different specialisms and social care (including support chasing a 3 month delayed attendance allowance and blue badge renewal)."*

Another person commented:

*"Having a good social worker who works for you and knows what you are entitled to."*

Besides being supported by professionals with the health and care system, one person said that capable family members helped them:

*"A dedicated family member who acts as a strong advocate and can help navigate the complex system of the NHS and social care."*

A final group of responses emphasised the role of individual action in the process of seeking and receiving care. This included, *"Individual care"* and *"Self-management"*, as well as ensuring regular checkups:

*"In my own case I do get regular checkups every two years without having to go back to the GP to start the cycle all over again."*

One person also commented on their own positive interaction with their local health providers:

*"Working with a variety of people at my GP surgery and the [X] Primary Care Network seems to work well."*

### 3.2.4 What could be better or different?

A final question asked for suggestions of what aspects of joined up care could be changed or improved. The following list is a summary of the main responses:

- Services working more closely together, especially between health and social care.
- Better communication and information-sharing among providers, and ensuring health records read and updated on the NHS app.
- Ensuring there is a dedicated or 'named' 'patient advocate' responsible for coordinating with providers, patients, and caregivers across services.
- A joint health and social care budget to ensure equitable access to care and to make financing easier and more efficient.
- More available services to improve access to care, including GP appointments, mental health support, local x-ray facilities, and patient transport service.
- A recognition that services users and caregivers are not experts in the health and social care system, and may be unfamiliar with the terminology that professionals use.
- Greater transparency regarding social care structures and decision-making.

### 3.3 Case stories

The following case stories are anonymised summaries of telephone interviews with two survey participants. They are included to provide more detailed, contrasting accounts of how different people can experience care and how they might relate to the goal of delivering joined up care.

#### Story 1 – Experience of a husband recounting his wife’s end-of-life care

*...when she was in hospital...very unwell, I spoke to the doctor consultant in the complex medicine ward. And she said "I am sorry to tell you, but I think we need to ask you to sign the end-of-life form", so I signed it...Sometime after that, our daughter said "I think we really ought to get Mummy back home". Believe it or not the doctor had already asked for approval of the end-of-life form, the approval was granted and between the Tuesday and the Thursday, it was all put into place. And she came home on the Thursday. All of the actions up until getting home, with one exception, were absolutely fantastic. [X organisation] came to fit a special bed on the Tuesday night which was fantastic and she had a downstairs bedroom. The medications were good, the assessments and all of those things. And we were fortunate because the caring company, who had cared for [my wife] for essentially three years, were able to arrange the care on the day that [she] came home and everything was in place.*

*The only problem was that the ambulance patient transport service said we'd have to have a maxi carrier for 4 people to get her into the room due to the layout of the house. So the doctor rang the ambulance team who normally take people into the hospital and asked them...which is I don't think they had ever done before, and they did the job beautifully. Straight into the bed...*

*Within 2 or 3 weeks, the caring company obtained the funds back from NHS from the end-of-life Care Authority. I was shocked that it was done quickly and so considerately. I didn't expect that they would pay for that care.*

*I think because [my wife] had been under occasional visits from district nurses and therefore had a yellow file, so I think she was known to them. It meant that they were aware of [her] and one fantastic district nurse was responsible. So the nurses and the palliative care special nurse, and the district nurse, Team Leader, all knew exactly what was required.*

## **Story 2 – Challenges faced by a mother seeking care for her son**

*My son needs access to loads of services: the GP surgery, [various specialist care services], which is both the learning disability community team and the physical disability team. Then there's the [other specialist services]. There's occupational therapists and the notorious social services.*

*There's very little communication between the different services and you've got to really push for everything and know who to ask for what. They don't tell you things. There's no map of the services so it's all guesswork.*

*For example with orthotics, they'll say, 'No, you can't have that particular pair of shoes that you need, because you've got the wrong kind of disabled feet'. And then you find out from another department that there's a grant available that we weren't told about that would have paid for the shoes, but by then it's too late. It's like trying to get through a maze blindfold.*

*You know, everything's done by zoom now, so people don't get to know you, social workers don't get to know, you get passed from one to the other, you don't get the same one. That's a big thing not having the same particular social worker, but could also be a medical person with ongoing treatment. I do realise that social services is on its knees, and they are really struggling and overworked and their staff keep leaving, that really bounces off on to us as service users. And what it also means is that they don't treat us with respect or with any kind of empathy, because they're working in a situation that I gather where there's no respect to empathy for them. You know, nobody will ever tell you how's it's run? How's it's constructed? Who are these supervisors? What are they? What do they do? What outcomes? What was the duty officer that you have to phone up? Who*

*are they going to be? How does it work? They're going on and on about transparency, which is a key word but they're just completely opaque.*

*We've got [specialist equipment] that social services bought for us about 15 years ago. It's great that they bought it. But what they didn't tell me was that, of course, everything starts needing repairs, you know, it's got a complicated electronics inside. So that started needing repairs. And again, I thought, well, we can pay for that from the direct payments, because we had a huge excess. And so I thought I paid for it with that. Anyway, then I was told "No, no, no, you can't do that. We only pay for repairs for the first five years." The supervisor social worker and the head of the OT department who both came round at my insistence to meet us personally said, "What you have to do is apply to us for [new equipment] and we will give it to you." We don't need a new one. What a waste, and they cost £5,000.*

*They send people round to inspect [other equipment] so often that I'm pulling my hair out because I said, we're not a care home, we're just one person...They have to send people around for insurance purposes, which is again, a huge waste of money. We were told that we had to have our customized [components] replaced. And the company has changed by now. So another company will come around and measure up all over again...Now that was about two hours of time, a huge amount of money. Because who knows how much that company charged...? All of this just makes you want to cry.*

*When you get a new person from, you know, OT or social services or anything, they have no idea what the other person did or said. There must be some sort of record somewhere but people can't be bothered to read things these days...Services are out to punish us and it's so irrational.*

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## 4 What did we learn?

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Many of the survey responses illustrated that people perceived a need for, and benefits of integrated care, especially services and providers working together and communicating well, patient-centred care, and getting support to navigate the system.

People generally wanted to play an active role in their care and have a say in decisions. However, we heard that people might not feel or be included in conversations about their care, or are not given the opportunity to participate in the decision-making process. In some situations, this made people feel like they were treated more as consumers of care and not as a "whole person".

There needs to be recognition that services users and their caregivers are not experts in how the health and social care systems work and may be unfamiliar with the terminology used by professionals. They might not know the most appropriate course of action or who they should contact. This is where suitable 'named' individuals can be important to take overall responsibility for a person's care, offer advice and support, and act as 'gatekeepers' to providers and services.

It seems reasonable to wonder how integrated care can fully work when the health care system is experiencing current demand and supply pressures. For example, how can comprehensive care be effectively planned and delivered across services with chronic staffing shortages and a lack of appointments in primary care?

This was a rapid research project with some obvious limitations. A small sample (38 survey responses and five telephone interviews) meant that the findings only represent a very small number of people from specific demographic groups. Therefore, they might not reflect the experiences of Oxfordshire's residents more generally. Survey responses were sometimes difficult to interpret, mainly because there was insufficient information to understand the background and context of care or which services were involved, or not.

However, this report might complement other, more rigorous work that contribute to more successful implementation of integrated care in Oxfordshire.

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## 5 Useful links

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Oxfordshire Integrated Improvement Programme – powerpoint presentation to Health and Wellbeing Board [PowerPoint Presentation \(oxfordshire.gov.uk\)](#)

Oxfordshire Health and Wellbeing Board Meeting papers- for information and reports on Oxfordshire Better Care Fund, and hospital discharge models [Browse meetings - Oxfordshire Health & Wellbeing Board | Oxfordshire County Council](#) and October 2023 report ([Public Pack](#)) [Agenda Document for Oxfordshire Health & Wellbeing Board, 05/10/2023 14:00](#)

Oxfordshire Place Based Partnership [Agenda September 2022 \(healthwatchoxfordshire.co.uk\)](#) and see Oxfordshire Health and Wellbeing Board reports for regular updates on activity.

Department of Health and Social Care: Health and social care integration: joining up care for people, places and populations. Feb 2022. [Health and social care integration: joining up care for people, places and populations - GOV.UK \(www.gov.uk\)](#)

Joint Forward Plan (Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board) [Joint Forward Plan | BOB ICB](#)

Integrated Care Strategy (Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Partnership) [Joint Forward Plan | BOB ICB](#)

Integrated Care. Kings Fund resources. [Integrated care | The King's Fund \(kingsfund.org.uk\)](#)

Better Care Fund [NHS England » Better Care Fund](#)

Oxfordshire County Council 'The Oxfordshire Way' [Oxfordshire Way strategic vision | Oxfordshire County Council](#) and infographic [Annex 1 The Oxfordshire Way illustration.pdf](#)



**Healthwatch Oxfordshire** - our friendly staff are here for you to help answer questions or give you information on health and care services in Oxfordshire. If you need more information or advice, call us on **01865 520520** from 9am-4 pm Monday to Friday.

To find out more about Healthwatch Oxfordshire please see **[www.healthwatchoxfordshire.co.uk](http://www.healthwatchoxfordshire.co.uk)**

If you would like a paper copy of this report or would like it in a different format or language, please get in touch with us:



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